

Letter to Chronic Fatigue Syndrome Advisory Committee

It is a Saturday morning in early May a few years ago and my girlfriend (now my wife) and I decide to go for a 4 mile run since the weather outside is beautiful. A couple of years later it is a similar Saturday morning in early May and what do we do? I sit on the couch and my wife either lies in bed or on the couch all day. Why such the change in what we are doing? Is it due to laziness, not feeling like running or something else? If you guessed something else, you are correct. My wife has finally been diagnosed with Chronic Fatigue Syndrome.

Things have definitely changed in ours lives the past few years. My wife went from being someone who would work 60-70+ hour work weeks, workout, go out with friends, volunteer, etc, to someone who couldn't even get out of bed (spending 20-22 hours in bed). Before she was diagnosed with CFS, she went to see at least 10 different doctors over the course of a couple of years. She was fatigued all the time and was gaining 5 pounds a month. All of the doctors told her that she was just depressed and that if she worked out and dieted she would feel better. One even put in his notes that he thought she had a compulsive eating disorder. She did everything that the doctors had asked her to do, but there were still no improvements. She could have given up, but she didn't. She knew there was something that the doctors were missing. We made a risky decision to have her stop working even though the doctors didn't know what was causing her fatigue. Luckily, not long after she stopped working, we were able to find one doctor who specializes in CFS and practices in the same metropolitan area where we live.

I look back on the time before she got diagnosed and I feel guilty for the fact that I used to get annoyed with my wife when she would not get up and go to work. I knew that she wasn't depressed, just frustrated because she felt so bad all of the time. I just thought that she just needed to workout and diet to lose some weight and this would begin to make her feel better. I was basing this on what the doctors had told her and me. I figured she could just suck it up and push her way through it. I didn't know at the time that her pushing herself only made things worse. I tried to be as supportive as I could, but I just didn't understand. I could see the effects CFS was having on her, but we didn't know what it was at the time.

Since she was diagnosed with CFS, we have had to make some changes to our lives, we sold one of our cars and I now take public transportation to work. We don't do many things with friends because it is hard to commit to anything because we never know how she will be feeling. Our lives have basically been put on hold as we don't know how she will be feeling from day to day.

She has made considerable progress the last two years; she no longer is in bed for 20-22 hours a day, but there is still a long way to go in her recovery. At least she is able to do some activity in 1-2 hour increments and I don't have to carry her up our stairs and put her in bed anymore. One thing that is troubling is we don't even know if or when she will ever get back to her pre-CFS self.

If I could personally change/improve things, I would change/improve the following:

1. **More funding for research-** With more research, the illness will become better understood and hopefully will be easier to diagnose and treat.
2. **More public awareness of what it is-** Most people don't understand what CFS is or how it affects those who have it. People tell her I know how you feel; I am tired all the time as well. Nothing could be further from the truth, but most people don't know that.
3. **More education for doctors-** If more doctors were aware and better informed that CFS is a "real" disease they would be able to diagnose it sooner.

Thank you in advance for taking the time to read this letter and for all that you are doing to further the cause. I appreciate all your time and effort.